



Ucare

The Caregiver Guide

Module 15

Caring for a Family Member with Mental Illness

Leader Guide

UCARE Module 15

Caring for a Family Member with Mental Illness

PURPOSE

Module 15 will provide caregivers of a family member who has mental illness with facts about mental illness. In this module we will discuss symptoms of mental illness including emotional reactions that are common among family members, and information about local programs that are available to help family members and persons with mental illness.

OBJECTIVES

After completing this module, participants will be able to:

1. List basic facts about mental illness and recovery.
2. Recognize symptoms of mental illness.
3. Identify stages of emotional reactions among family members.
4. Express feelings about what it's like to be a spouse, parent, or sibling of someone with serious mental illness.
5. Identify community resources that provide support to families and individuals with mental illness.
6. Describe a specific action that caregiver will take in the following week to take care of him/herself.

SLIDE 1

UCare: The Caregiver Guide Caring for a Family Member with Mental Illness

INTRODUCE

Introduce yourself and allow everyone present to introduce themselves and explain their role.

NOTE

This is an excellent time to set the tone of the session. Be relaxed and focused. Remember names.

TELL

The handouts are yours to take home. There is room to write on the handouts during the session.

ASK

What would you like to get out of the training today?

NOTE

Put responses on a white board and during the session refer back to them and put a check by specific topics discussed. Any personally identifiable information discussed in the group must be kept confidential. Please try not to use the name of the person that you are a caregiver for.

If participants request topics that are covered in other UCare modules, tell them they can request additional training. Point to the list of UCare modules on the back of the participant booklet.

This module WILL NOT cover technical questions about eligibility for public programs such as Medicare, Medicaid, Alternatives or

Caregiver Support programs. These questions will need to be answered by an eligibility specialist for the particular program.

SLIDE 2

After this workshop you will be able to:

- List basic facts about mental illness
- Recognize symptoms of mental illness
- Identify stages of emotional reactions among family members

SLIDE 3

In addition you will be able to:

- Express feelings about what it's like to be a family member of a person with mental illness
- Identify community resources that provide support to families and individuals with mental illness
- Describe a specific action that you will take in the next week to take care of yourself

NOTE

Refer to additional objectives requested by participants.

TELL

This one hour workshop is designed to help caregivers of a person experiencing mental illness. It will give you facts about mental illness and help you understand the emotional reactions that are common among family members and caregivers. The workshop will also give information about local programs that are available to help you as a caregiver for the person with mental illness.

Although it is not uncommon for an individual to have mental illness and a substance abuse problem, we will not discuss this in this module. If this is your situation, please see me after class and

we can talk about possible resources. (Resources are in the Additional Information folder in the Leader Toolkit.)

In this workshop we will be giving examples of our experiences that may be difficult for some. Remember to respect the confidentiality of group members. What is shared among the group does not leave the room.

SLIDE 4

Facts about mental illness and recovery:

- Mental illnesses are biologically-based brain disorders. They cannot be overcome through "will power" and are not related to a person's "character" or intelligence

TELL

Here are some important facts about mental illness and recovery: Researchers have shown indisputably that mental illness is caused by chemical and physical changes to the brain. The belief that serious disorders such as schizophrenia or bipolar disorder are caused by poor parenting or bad moral character is a myth. Yet the stigma of mental illness as a sign of bad character remains.

ASK

Thinking back to your childhood, do you remember an association with a person who had mental illness? What was your attitude toward a person with mental illness when you were young? What messages did you get from your parents or other family members about mental illness?

NOTE

Read the text on the slides out loud.

SLIDE 5

Facts about mental illness:

1. Mental illnesses strike individuals in the prime of their lives, often during adolescence and young adulthood – All ages are susceptible, but the young and the old are especially vulnerable

SLIDE 6

More facts about mental illness (continued):

2. Without treatment the consequences of mental illness for the individual and society are staggering: unnecessary disability, unemployment, substance abuse, homelessness, inappropriate incarceration, suicide and wasted lives
3. The economic cost of untreated mental illness is more than 100 billion dollars each year in the United States

SLIDE 7

Facts about the process of recovery:

1. The best treatments for serious mental illnesses today are highly effective
2. Yet, treatment is not a “cure” -- symptoms can come and go in cycles
3. Between 70 and 90 percent of individuals have significant reduction of symptoms and improved quality of life with a combination of medication and psychosocial treatment and supports

ASK

What are the challenges for your family member? What are the challenges for you?

SLIDE 8

More Facts about the process of recovery:

4. Early identification and treatment is of vital importance
5. By getting people the treatment they need early, the process of recovery may be accelerated
6. Treatment may protect the brain from further harm related to the course of illness

ASK

How long did it take for you to identify the mental illness? How long did it take for your family member to identify their mental illness? How long have they been in treatment? Have you seen signs of recovery?

SLIDE 9

Symptoms and treatment of mental illness:

- National Institute of Mental Health (NIMH) website: www.nimh.nih.gov
- National Alliance for Mental Illness (NAMI) website: www.nami.org

TELL

Treatment for mental illness is usually directed by a diagnosis. Once a person is given a diagnosis, that “label” may guide what type of treatment will be recommended. This module will not answer any technical questions you may have about your family member’s diagnosis or treatment. However, you may want to research on your own what is known about the diagnosis or “label” that has been given to describe your family member’s condition. The Participant Booklet contains brief descriptions of major mental conditions beginning on Page 14. These one-page descriptions indicate symptoms and the types of treatment usually

recommended for each condition. The information was obtained from the National Institute of Mental Health website.

NOTE

Emphasize that this workshop will not answer any technical or scientific questions about a condition, diagnosis or treatment. The trainer is NOT a clinician.

SLIDE 10

Symptoms of Mental Illness:

1. New behaviors you now see
 . . . Changed due to the illness
2. Old behaviors you used to see
 . . . Lost due to the illness

ACTIVITY 1

Ask participants to go to page 5 of the Participant Booklet. Review the chart “Understanding Symptoms of Mental Illness.” Ask participants to read the left hand column and identify the behaviors in the chart that they have seen in their family member. When they notice these behaviors, do they realize these are part of the illness? What symptoms have been the most troublesome?

Then ask participants to read the right hand column of the chart. Which of these behaviors characterized their family members? Which behaviors do they miss the most?

SLIDE 11

Stages of emotional reactions among family members

TELL

The National Alliance on Mental Illness, or NAMI, is a non-profit organization that provides education, support and advocacy for those with mental illness and their family members. NAMI has identified three major stages of emotional reactions among family members as they learn to deal with the illness of a person. These stages of the grieving process do not start and stop at predictable periods of time.

- One may experience denial for a long time then move into anger and very quickly into depression.
- Family members' reactions may cycle around in and out of the various emotions.
- These stages that we will describe in this session come from the Family-to-Family class developed by NAMI. Their classes are available statewide. You may review the stages in the chart on page 8.

SLIDE 12

Stage 1. Dealing with the Catastrophic event

Crisis and shock:

- Feeling overwhelmed
- In a daze
- We don't know how to deal with it

NOTE

Read the text on the slides to the group.

TELL

The first stage is usually dealing with a catastrophic event. A crisis occurs and we don't want to believe it. We are in shock. We feel overwhelmed and dazed. It's common to feel guilt and shame. But we also want to rationalize what happened, to find an explanation

that makes it okay. In this stage we really don't know what to do or where to turn. We want things to become "normal" again.

SLIDE 13

Identify the stages from page 8 as we read this story.

TELL

Listen to this story. You may read along on page 9 of your Participant Booklet:

"Helen was a graduate student and teaching assistant at a local university. She had a second part time job off-campus at a research laboratory. She worked and studied 60-70 hours per week and went out on weekends to local clubs with her friends. Her parents were worried that she would "burn out" with working so many hours and hard partying. But they rationalized that Helen was young and she seemed to be handling everything okay. Besides, Helen was an adult and they didn't want to appear as if they were treating her like an adolescent."

SLIDE 14

Stage 1. Dealing with the Catastrophic event (continued) -

Denial:

- This is not really serious
- There is a perfectly logical explanation for this
- This will pass

NOTE

Read the text on the slides out loud. Continue the story. Have participants continue to review the stages on page 8 to identify the stages.

TELL

“As a teaching assistant, Helen was supposed to grade mid-term exams for the Biology class. Her professor continually asked her when they would be graded, but Helen kept making excuses. Finally, by the end of the semester Helen had not graded any mid-term exams and the professor had to ask another teaching assistant to grade the exams in time to submit the grades. Helen apologized to the professor and explained that her off-campus job had been very demanding and she was carrying a heavy school load this semester. She also apologized to the teaching assistant by taking him out to dinner because he had to do her work for her (grade the exams).

“The Biology professor considered firing Helen from her job as a teaching assistant before the next school year. He was reluctant because he knew she was smart and hard working, and he did not want her to drop out of school. In the end, she was allowed to keep her job for the next school year.”

SLIDE 15

Stage 1. Dealing with the Catastrophic Event (continued) -

Dawning of recognition:

- Hoping that this is not a long term event
- Somehow everything will magically go back to normal
- Hoping against hope

NOTE

Read the text on the slides out loud. Continue the story.

TELL

“At the beginning of her second year as a teaching assistant, Helen was assigned to a new professor. Because this professor had been warned that Helen tended to procrastinate, he set up a strict schedule for her grading to be completed. Helen agreed to and signed this schedule because she wanted to perform well after last year’s embarrassment. Despite all of Helen’s promises and the strict expectations of the new professor, the same thing happened and the exams did not get graded by the end of the semester. The professor tried to contact Helen at school and at home to get the exams back, but was unsuccessful. Finally he called her parents in another town to see if they knew where she was. Helen’s parents drove to her apartment where they found Helen hiding under her bedcovers. She had been in her apartment for a week – not eating or talking to anyone. They found the exams on her dining room table ungraded.

“Helen was admitted to an inpatient psychiatric unit to treat her depression. She was eventually diagnosed with bi-polar disorder.”

ASK

Can you understand how denial occurs and what it looks like?
What has been your experience?

SLIDE 16

Stage 2. Learning to cope

Anger / Guilt / Resentment:

- We start to blame the victim (person with mental illness)
- Insist that the person with mental illness “snap out of it”
- Harbor guilt, fearing that it really *is* our fault
- Torment ourselves with self-blame

NOTE

Read the text on the slides out loud.

TELL

In the second stage you learn to cope with the changes in your family member. Families feel as though they have been “through the mill” in seeking help through a mental health system. Families have been frustrated and disappointed in trying to get answers and satisfactory treatment. Families often feel “burned out” with trying to find answers and with living with their ill family member. They are at the angry stage of the grieving process and they have horror stories to tell.

SLIDE 17

Stage 2. Learning to cope (continued) -

Recognition:

- The fact that mental illness happened to someone we love becomes a reality for us
- We know it will change our lives together

SLIDE 18

Stage 2. Learning to cope (continued) -

Grief:

- We deeply feel the loss of the person we knew
- Our future together is uncertain
- Sadness that does not go away

TELL

Acknowledging your feelings and recognizing that this is an important part of the process is critical. With time, you have recognized the extent of the changes and understand that these

changes will affect the future of your family member and you as well. And the loss of the family member that you knew and concern about the future brings a deep grief.

ASK

What about you? How have you tried to cope? What does it feel like?

TELL

Taking care of yourself is often overlooked and the needs of other family members are often forgotten in the intense anger that follows this stage of frustration and powerlessness. Depression follows anger and feelings of hopelessness develop. Families at this stage need reassurance, hope and knowledge about how best to deal with their family member.

SLIDE 19

Stage 3. Moving into Advocacy

Understanding:

- Empathy for what our loved one is suffering
- Respect for the courage it takes to cope with the illness

SLIDE 20

Stage 3. Moving into Advocacy (continued) -

Acceptance:

- It's nobody's fault
- It's a sad and difficult life experience, but we will hang in there

SLIDE 21

Stage 3. Moving into Advocacy (continued) -

Advocacy / Action:

- Focus your anger and grief to advocate for others
- Join public advocacy groups and become involved

TELL

Stage three moves from the despair and guilt and grief to an understanding of the challenges your family member is facing and the courage they have to deal with the illness.

Acceptance is recognizing that no one is to blame and that you can move forward. It is at this point that you may become an advocate and use your understanding to join others in support and advocacy activities.

ASK

Are you able to imagine getting to the point of focusing your anger and becoming an advocate? Have you been here?

SLIDE 22

Community resources:

Community resources provide support to families and individuals with mental illness.

NOTE

Point out resource information in Participant Booklet starting on page 11. Go through the sections and read the major headings. Allow participants a few minutes to review.

TELL

There are some good community resources that can help families find the information they need. NAMI has a Family-to-Family education program that is a free 12-week course. In addition they have a course called “Bridges” for the person with mental illness. The Resource section in the participant booklet gives contact information. They have support groups as well as one-on-one mentoring for family members as well as consumers. Staff and volunteers can provide the appropriate support and help that is needed.

ASK

Has anyone had experience with a support group?

TELL

It is important to recognize that the emotional pressure and physical strain can be detrimental to your health also. As a caregiver you need to be sure to see a physician regularly and if you begin to feel unusually tired or depressed, please let a professional know.

As I’ve said, taking care of yourself is often overlooked and the needs of other family members are often neglected. Families need reassurance, hope and to learn how best to deal with a loved one.

ACTIVITY 2

Turn to Page 13 in the Participant Booklet and complete this page as a group.

What advice would you give to someone in a similar position (as a spouse, parent, sibling) caring for a person with mental illness? What do you do to take care of yourself? Write down one thing you

will do FOR YOURSELF this week. Share this with a neighbor or the group.

NOTE

Leader should have chosen one of the ‘Take a Break’ exercises from the Leader’s Toolkit

TELL

We have one activity remaining. An important part of caregiving that is often forgotten is YOU, the caregiver. You need to take care of yourself.

SLIDE 23

Take a Break.

NOTE

Leader should have chosen one of the ‘Take a Break’ exercises from the Leader’s Toolkit.

TELL

We have one activity remaining. An important part of caregiving that is often forgotten is YOU, the caregiver. You need to take care of yourself.

Ask participants:

- What do you do for you?
- Discuss the answer to this question briefly

ACTIVITY 3

- Lead the participants in the ‘Take a Break’ exercise you have chosen.

- Impress on the participants that it is important for them to do something for themselves each day. Ensure they understand the “Take a Break” card. Review with them several times and ask questions to ensure understanding.

SUMMARY

Remember that you have courage, strength, compassion, power and wisdom. Thank you for your participation. You’ve been a great audience. Please complete the Feedback Sheet. I welcome your comments and appreciate your interest. I wish you the best in your efforts to care for your loved one with mental illness. If you have additional questions or concerns, I would be happy to talk with you following this presentation.